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Research Study

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Assessing Advance Care Plan Discussions in Hospice Day Care

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ABSTRACT

Background: Advance care planning (ACP) is a voluntary discussion between an individual and their care providers. The primary purpose is to identify and document a person's wishes and preferences for future care.

Method: Within Betsi Cadwaladr University Health Board (BCUHB) an ACP document which records the process of advance care planning has been developed, piloted and approved for use within North Wales. The BCUHB ACP document can be used to structure and document ACP discussions with patients. It is a patient-held record of these discussions that with the consent of the patient may be shared if appropriate with those important to the patient and/or healthcare professionals. ACP discussion opportunities and documentation of patients' wishes and preferences for future care have been introduced into hospice day care in North Wales.

Outcomes: This paper reports on the preliminary outcomes, lessons learnt and how they are informing the way forward with this challenging local initiative whilst contributing to the international ACP picture.

KEY WORDS: Patient-held; Wishes and preferences; Monitoring ACP activity.

ABBREVIATIONS: ACP: Advance Care Plan; NOK: Next of Kin; BCUHB: Betsi Cadwaladr University Health Board; HCP: Healthcare Professional.

INTRODUCTION

Advance care planning (ACP) aims to identify a person's wishes and preferences in anticipation of a potential deterioration in their condition in the future, with possible associated loss of capacity to make decisions and/or ability to communicate wishes and preferences to others. Department of Health 'Together for Health-Delivering End-of-Life Care'¹ sets out the Welsh government's strategy for end-of-life care whilst providing a comprehensive framework aimed at promoting high quality care for children and adults approaching the end-of-life in all care settings, stating that 'individuals should be supported in planning for the end-of-life with the help of professionals'.

One of the key aims of the strategy is to ensure, as far as possible, that people approaching the end-of-life have their needs and preferences for future care met.

Every individual may have a different idea about what constitutes a 'good death' for them but for many, the common factors are:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings.

Being in the company of close friends and family ACP can maximise patient autonomy and emerging evidence suggests that this can lead to greater satisfaction with care.² Among healthcare professionals knowledge of ACP is patchy and many patients are unaware that they can document their wishes and preferences in this way.

Sometimes the task of documenting wishes and preferences for future care can be overwhelming. Utilising a pro-forma template can assist in structuring and supporting discussions around ACP whilst simultaneously organising and documenting wishes and preferences, breaking the task down into manageable 'chunks' or sections.

Within Betsi Cadwaladr University Health Board (BCUHB) an ACP tool which charts the process of advance care planning has been developed, piloted and approved by BCUHB for use within North Wales. The BCUHB ACP template is comprised of five sections and utilising this template as a structure, palliative care providers are seeking to improve the opportunities for ACP discussions and achievement of patient's documented wishes and preferences at the end-of-life.

Starting an important discussion concerning wishes and preferences for future care with patients attending hospice day care can be challenging. Group discussions can be an acceptable way of introducing the topic followed-up with one-to-one conversations between healthcare provider and patient. The healthcare professional leading the discussion is perhaps best placed to tailor the approach to ACP discussions to the individual patient.

Good communication skills are essential, for starting, facilitating and managing the conversations.^{3,4} Listening skills are key as patients will often give cues for putting the conversation on 'hold' if an area is particularly difficult for them to contemplate.

Re-visiting issues may be essential if the patient is to address all their concerns around future care. Sensitivity is also an essential part of these discussions as well as allowing the patient to explore issues at their own pace.^{4,6} Sharing documented wishes and preferences for future care with healthcare providers, and/or those important to the patient is strongly advocated but can only take place with the consent of the patient. Regular review of the ACP is also recognised as good practice since wishes and preferences may alter or fluctuate subject to disease progression and consequently change over time.⁷

Risks and Benefits of ACP discussions: There are risks and benefits to ACP discussions.

Some of the risks include:

- Patients not understanding their illness, lacking insight into their condition and prognosis, or lacking capacity to undertake a discussion;

- Patients changing their mind about what they would really want: factoring in an agreed review date is good practice;
- Excluding families: including those important to the patient in the ACP discussion is highly advocated although this has to be done with the explicit agreement of the patient.

Benefits are multiple for patients, families and healthcare staff. Patients who have completed an ACP will say that; *"thinking ahead and making realistic plans were useful,"* also *"it (completing the ACP) brings peace of mind,"* some reported that they *"experienced a feeling of comfort and security once all their wishes and preferences were documented in the ACP"*.

(Author's Personal Communication)

ACP discussions can deepen the family bond, save family anguish over making tough decisions and bring a sense of relief knowing that they have contributed to delivering the best possible care for their relative.

For healthcare staff, increased job satisfaction, stronger team working and improved communication skills are but a few of the recognised benefits.

Method

The aim of this implementation project was to introduce and monitor progress of, advance care planning opportunities for patients attending hospice day care, utilizing a tool to chart the process of advance care planning.

To inform the evaluation of the study aim the objectives of monitoring and recording progress of ACP discussions and documentation in the form of a patient held ACP document were undertaken.

North Wales has four adult hospices spread across a wide geographical area and each hospice provides day care including a range of different therapies for patients. The initial introduction of ACP discussion opportunities reported here was sited at the hospice in the Eastern part of the region. The eastern hospice provides specialist palliative care services to patients and their families across an area stretching from Wrexham, Flintshire and East Denbighshire to Barmouth, and also accommodates patients from the border towns of Oswestry and Whitchurch. Services include a 12 bedded in-patient unit and a 15 patient Day Care unit—open 3 days a week, with a 'drop-in' programme once a week.

Patients with a diagnosis of cancer and other life limiting illnesses are referred to hospice day care which offers nursing support, financial advice, physiotherapy, complementary therapy and a socialising environment. Engagement with the process of advance care planning is entirely voluntary, it is a patient led, patient driven process with the resulting advance care plan being a patient held record.

The day care unit provides the opportunity for patients to visit on the same day each week, between the hours of 10 am and 3 pm, for an initial period of six weeks, which is then reviewed.

Prior to their first attendance patients are assessed in the out-patient clinic by a member of the senior clinical team, and subsequently discussed within the multidisciplinary team forum.

In the day care setting conversations around ACP are opened at any stage, from a patient's initial assessment onwards, by any member of staff with the relevant communication skills and ACP knowledge. Initial discussions can be held in a group context with the next steps on a one to one basis or if relevant on a one to one basis from the outset. ACP documentation is introduced appropriately and used to structure the discussions as patient's wishes are explored.

Following discussions around ACP and the introduction of the BCUHB ACP document, each patient's reaction to the discussion and expressed interest in documenting their wishes and preferences for future care is recorded utilising a locally designed data capture 'log'. The following results are obtained from detailed ACP discussion opportunity data recorded on the log for patients registered at the day care unit in November 2015.

RESULTS

In November 2015 a cohort of 28 patients registered for active day care was identified. Exclusion criteria covered those patients who were only attending as a one off visit or were attending for a session of complementary therapy. This cohort of 28 patients was followed through day care and any admissions to the in-patient unit for period of 12 months or until death occurred.

Of these 28 patients the topic of advance care planning was raised with 24 patients. The four patients not involved in ACP discussions were reluctant to participate for a variety of reasons, including mental health, having a different goal focus, recent bereavement and reluctance to face the future in any way at all.

All four of these patients are alive at the time of writing and may yet be interested in participating in ACP discussions.

Of the 24 patients introduced to the topic of ACP, 21 patients engaged in discussions or expressed wishes around future care. Three patients did not wish to pursue ACP whilst attending day care but one patient did go on to make his wishes known to his community team before passing away. The BCUHB ACP document was given to the other two patients, one of whom passed away before documenting her wishes and preferences in the document.

Of the 21 patients engaging in discussions around ACP and expressing wishes for future care, one patient was admitted to the hospice as an in-patient when their final preferences

were made known, and for one patient discussion is on-going. A total of 19 patients have shared their wishes and preferences with family members (6), or community teams (13). Of these 13 patients, 12 have subsequently died. Figure 1 for progress of patients in ACP discussions.

DISCUSSION

The experience reported here demonstrates the complexity of capturing ACP discussion and decision-making.

Data capture is always going to be a balance between over burdening the patient and informing and refining the ACP discussion opportunity and documentation process. Keeping a record of the time frame over which the ACP discussions take place and the documentation occurs is valuable since 'time' is not a commodity all patients attending hospice day care have an abundance of. The preliminary outcomes reported here indicated that the way ACP data was recorded needed to be refined to allow the collection of finer detail about factors enabling or prohibiting the completion of an ACP. Knowledge about barriers to completing an ACP can help to orientate future discussions about ACP and may assist some patients to overcome the perceived barriers and approach the task of drawing up an ACP.⁸

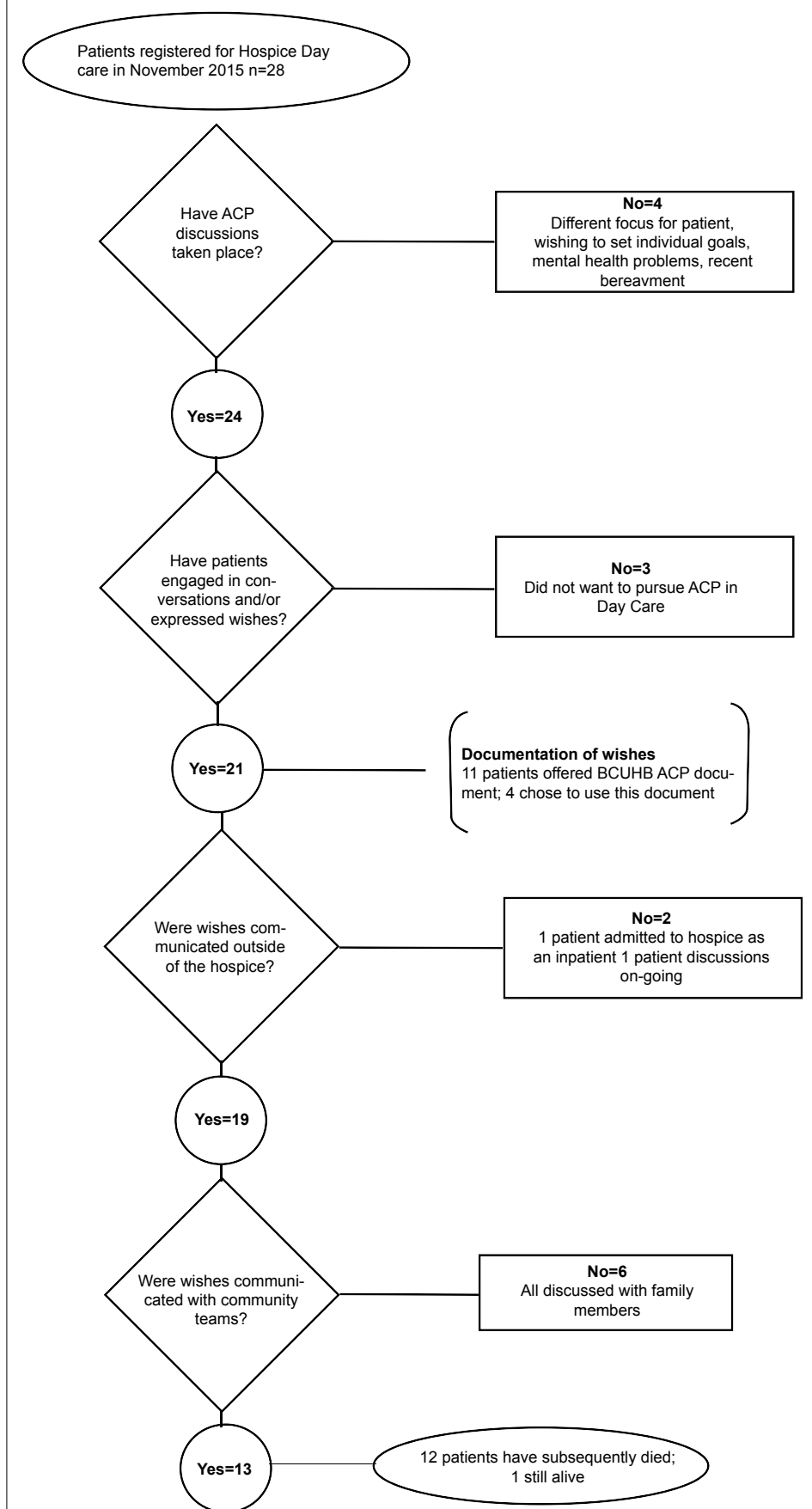
Keeping a detailed account of the time frame for ACP discussions and documentation is useful too, since it may transpire that approaching patients earlier in their disease trajectory is more conducive to discussing and documenting wishes and preferences for future care.

Identifying the shortfalls of the initial 'log' was a valuable element of this exercise and informed the development of a detailed ACP Log. See appendix A.

There are many preferences that patients may have identified and shared with those important to them towards the end of their lives, and they will be individualised and personal. Preferred place of death (PPD) is a preference which can be identified and recorded. This is often used as a concordance measure and is increasingly included as an outcome measure when new strategies are implemented.⁹ The emerging evidence for the strength of concordance measures is varied and agreement between expressed preferences and actual care can often be less than 50%.^{10,12}

The ACP process is multi-factorial and as such very difficult to evaluate and most evaluations rest on a basic count of how many ACP discussion opportunities are offered, and how many discussions result in an ACP being documented. This simple metric only reveals frequency and cannot inform much more than 'ticking a box.'

Capturing the quality of the conversation and the accuracy of the documentation together with establishing that care was delivered in line with the patient's documented wishes and preferences is a stronger metric but involves a more complex

Figure 1: Progress of Patients in ACP discussions.

evaluation. A recent systematic review concludes that a battery of measures is required to effectively evaluate ACP uptake and monitor sustainability. The study advocates international dialogue to determine consensus on an optimal framework for evaluation and to facilitate comparisons across healthcare systems.¹³

CONCLUSIONS

The preliminary outcomes reported here rest on the starting of important conversations, recording who has had an ACP discussion opportunity and what the outcome was. Our initial experience was helpful in process improvement, we plan to refine the tool by reviewing the information gathered and assessing how much information is not being recorded that could prove to be useful for future quality improvement. For most individuals their ACP will evolve over a period of time, following thought, conversations with those important to them and discussions with health care professionals.

The pace of these discussions must be dictated by the patient involved, and healthcare professionals require judgement, communication skills and sensitivity when introducing the topic, developing the breadth of the conversations and exploring personal concerns.

ACP documents can provide a framework for patients to develop their thoughts and for professionals to guide conversations. Most patients require sensitive ongoing support to explore the issues they raise and express their wishes. Our initial challenge is to facilitate this process at an individual pace. Further challenges include keeping accessible records to allow different professionals to engage with and develop ACP discussions and appropriately utilise the information that has been shared with the express consent of the patient. Formulating effective methods for evaluating the implementation of ACP and monitoring sustainability are challenges that await us and we look forward to reporting on them in the future.

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CONFLICTS OF INTEREST

The authors have no conflicting interests with respect to this paper.

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Appendix A

Summary Sheet & Log



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Affix patient Identifier here



Advance Care Plan (ACP)

Use this form for persons **WITH** decision making capacity

A: About Me		
I prefer to be known as:		
I have documented my wishes & preferences for future care in an ACP	Yes	<input type="checkbox"/> No <input type="checkbox"/>
My wishes & preferences have been documented elsewhere Where?	Yes	<input type="checkbox"/> No <input type="checkbox"/>
I have made my will and those important to me know where it is	Yes	<input type="checkbox"/> No <input type="checkbox"/>
I have an advance decision to refuse treatment (ADRT)	Yes	<input type="checkbox"/> No <input type="checkbox"/>
I have treatment escalation plan (TEP) or other ceilings of care explained and drawn up for me	Yes	<input type="checkbox"/> No <input type="checkbox"/>
I have a DNACPR form in my notes	Yes	<input type="checkbox"/> No <input type="checkbox"/>
B: Personal values		
My advance care plan (ACP) is held by:	and kept in:	N/A
My Lasting Power of Attorney LPA is:		N/A
My wishes around tissue/organ donation are:		N/A
If I am nearing death I would like the following: (include spiritual, cultural/preferences)		
The place I would prefer to die: e.g. Home, Hospital, Nursing Home, Hospice.		
My Declaration		
I have had this summary sheet explained to me and I understand its purpose. I also understand that I can change my mind regarding these choices at any time.		
This summary sheet will be kept in my notes.		
I do/do not consent to share the information on this form with persons and services relevant to my health.		
Name Print:	Signature	Date



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Affix patient Identifier here



Discussion	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Notes	Date of Death	Preferred Place of Death
ACP discussion opportunity? Yes/No															
If No: Thinking about it?															Actual place of death
Outright Decline? Yes/No															Achieved?Y/N
Re-presented? Yes/No															If Not Why Not?
Was this a group discussion or 1:1?															
Document													Notes		
BCUHB ACP Document? Yes/No?															
Which sections?															
If No: Why not?															
Other ACP Document?															
Sharing														Notes	
Shared ACP Document?															
Shared with whom?															
Review Date Agreed & Documented?															
"Impact"														Notes	
Appropriate to contact NOK after death?															
Signature of HCP															